



Stuck in the Hospital



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Introduction

The Office of Developmental Disabilities Ombuds (DD Ombuds) is a private, independent office focused on improving the lives of persons with developmental disabilities in Washington State. The legislature gave the DD Ombuds the duty to monitor procedures and services provided to people with developmental disabilities; review facilities and residences where services are provided; resolve complaints about services; and issue reports on the services provided.¹ The following is a report on a systemic issue the DD Ombuds identified through its provision of services to people with developmental disabilities in Washington State.

People with developmental disabilities are stuck in hospitals

In spring of 2018, the DD Ombuds began receiving complaints about adults with developmental disabilities stuck in a hospital without any medical need. Most of these individuals were Developmental Disabilities Administration (DDA) clients who had been receiving residential services. Some individuals went to the hospital for a medical condition, but when they were ready for discharge, they had no place to go because their residential services provider had terminated their services. Other individuals were dropped off at the hospital by a provider who could no longer manage their care. These individuals with developmental disabilities then spent weeks or months in a hospital because DDA could not locate available residential placement with staff to provide care. As a result, these individuals had to live in hospitals while waiting for residential placement.

Hospital staff are not trained to provide support to people with developmental disabilities and hospitals are often stressful living environments. Many complaints the DD Ombuds received reported the safety of the staff and DDA client were in jeopardy, and the DDA client's mental health was declining in the hospital setting. Additionally, hospitals reported that, because there was no medically necessary reason for the individual's hospital stay, there was no mechanism for hospitals to be reimbursed for costs of housing individuals awaiting residential placement. This situation is dangerous for the individuals involved and costly to the medical system.

Hospitals as crisis placements

The following section contains client stories and quotes from hospital staff regarding hospitals as crisis placements for people with developmental disabilities.² These stories and quotes highlight situations in which a person with developmental disabilities was forced to live in a hospital setting, because their community provider could no longer support them and DDA

¹ See Revised Code of Washington (RCW) 43.382.005(4)

² Stories are examples from complaints made to the DD Ombuds office. All identifying information, including names, ages, and geographic locations, have been changed to protect confidentiality. Identities of quoted individuals have been changed to protect their confidentiality.

could not provide an appropriate crisis placement for the individual. Hospitals could not discharge individuals until another placement became available, leaving individuals in hospitals for weeks or months.

Quote: Manager of Social Work

“A DDA client was dropped off at our hospital by his provider. We contacted DDA and began a weekly accountability call with DDA and related stakeholders to work collaboratively on getting this person into correct care. We expected DDA to prioritize this situation because there was no medical need for this individual to be residing in any unit of our hospital. The confined space and hospital environment was not safe and resulted in this individual having assaultive behavior towards staff. The client was actually being triggered and over-stimulated by the hospital environment, exacerbating his stress and behavior exponentially. However, due to federal guidelines and concerns for his safety, we could not discharge him from the hospital until there was an appropriate residential placement available for him. We were expecting timely action to find a placement that had the appropriate skills to treat and support him, but no placement was available for months. As a result, our staff’s and the client’s well-being were both severely compromised for months because DDA could not locate a placement.”

No Supports Available to Prevent Hospitalization

Juan, an adult with a developmental disability, was assessed to need staff support 24 hours a day, 7 days a week in order to live independently in the community. Juan was able to locate a supported living provider that could provide the level of support he needed and he was able to move into an apartment.

For many months, the supported living provider reported to DDA that Juan’s behavior was changing and his safety was at risk. The provider reported that Juan was having sleep issues, was hostile towards providers, and was having trouble with balance. The provider documented and reported that Juan was falling down up to 10 times per week.

The provider and the DDA case manager agreed Juan needed extra supports in order to stabilize and live in a community setting. First, they requested medication management and additional in-home supports for Juan, but extra supports were not available. Next, the case manager requested placement at a crisis diversion bed to help Juan stabilize but there were

none available. Without extra supports, the provider did not feel they could keep Juan safe and made a plan to drop Juan off at a hospital and terminate his supported living services.

Juan ended up living in the hospital for 6 weeks, often in 4-point restraints, waiting for a crisis diversion bed to become available. Hospital staff did not have the training to provide residential and behavioral supports. The hospital used physical and chemical restraints to keep Juan from hurting himself and staff. Juan was eventually discharged to a diversion bed, but the cost and trauma of the hospital stay could have been avoided if services were available when the crisis was first identified by Juan's staff.

Quote: Registered Nurse

"Individuals with developmental disabilities get sent to the hospital because those who are trained to care for them cannot handle their behaviors. They are admitted to a medical floor where staff have no or little training or experience caring for them. The hospital environment is detrimental for most of them, too (loud noises and confined to a small room with little to do). This is not a safe plan, nor is it good for patients with these unique needs."

100 Days Wait for Crisis Placement

Tony was utilizing supported living services for the first time. Tony needed 24/7 support and moved into a home with two other individuals who were supported by the same residential services provider. From the start, the supported living provider had difficulty supporting Tony's behavior needs while maintaining services for their other clients. The provider determined they could not keep Tony or the rest of the household safe so they dropped Tony off at the local hospital and terminated his supported living services. Tony did not have a medical need to be at the hospital, so the hospital did not admit him. Tony lived in the emergency room department for over 100 days.

The hospital staff wanted to be able to support Tony, but were not trained to provide support for an individual with autism. As a result, Tony's interactions with the staff became increasingly unsafe. The hospital staff called the police, hired a security guard, and used physical and chemical restraints to manage Tony's behavior.

After two months of living in the emergency department, a designated crisis responder determined Tony's mental health had declined and he should be detained for mental health treatment. The crisis responder referred Tony to every mental health treatment bed in the State and none would accept him. He was denied due to lack of bed capacity or because the provider would not treat someone with an autism diagnosis. Tony lingered in the emergency

department for more than three months until a DDA crisis bed became available where he could receive support and treatment.

Quote: Registered Nurse

“Sometimes people with developmental disabilities are transported to emergency departments, even when they don’t have a medical need, because they don’t have anywhere else to go. Our goal is for patients to receive the appropriate care in the appropriate setting so that we can fulfill our mission of creating healthier communities. People with developmental disabilities should be placed in an appropriate community setting unless there is an acute medical need requiring hospitalization.”

Additional Complaints to the DD Ombuds of people stuck in the hospital

The list below describes some of the complaints received by the DD Ombuds since the spring of 2018. All of these people were clients of DDA and had been receiving residential services at the time they were taken to the hospital.

- A 32-year old woman was dropped off at the hospital by her supported living provider because of her challenging behaviors. She was stuck there for 30 days.
- A teenager was dropped off at the hospital by a crisis service provider due to behavior issues. He was stuck there for 6 weeks.
- A 60-year-old man was dropped off at the hospital in August 2018 by his nursing facility due to behavior issues, and the nursing facility refused to pick him back up. As of December 2018, he is still at the hospital waiting for placement.
- A young woman was taken to hospital by her supported living provider due to behavior changes. The woman was stuck at the hospital for 6 weeks waiting for a crisis bed placement.
- A 29-year-old man was dropped off at the hospital multiple times by his supported living provider due to behavior issues. He spent over three weeks in the hospital in a 2-month time period due to inadequate community-based behavior supports.
- A 40-year-old woman was dropped off at the hospital by her supported living provider due to challenging behavior and changes in temperament and stability. She spent over 5 weeks in the hospital waiting for a crisis bed placement.

- An 80+ year-old man was dropped off at the hospital by his supported living provider because he had increased medical needs. He was cleared for discharge within a couple days but spent almost 2 additional months living in the hospital waiting for a residential placement.
- A 35-year-old man was dropped off at the hospital by his supported living provider due to a decline in behavioral health. He lived in the hospital waiting for a residential placement for almost a month.
- A 25-year-old man dropped off at a hospital by his supported living provider due to behavior issues. He lived in the hospital for 3 months waiting for a crisis bed placement.
- A 21-year-old woman was dropped off at a hospital by her supported living provider due to behavior changes. She lived in the hospital for almost 4 months waiting for a residential placement.

Quote: Registered Nurse

“Patients in the hospital are often quite isolated. For people with developmental disabilities that are enduring very long stays in hospitals while they await placement, this isolation can negatively impact their behaviors, cause a decrease in functional ability, and increase loneliness and isolation. People living in hospitals typically lack appropriate developmental activities and peer group interaction, both of which are important for the overall general well-being of individuals.”

Policy Recommendations

This is a preventable problem. Changes can be made to the service system to ensure individuals with developmental disabilities have access to services that keep them in the community and prevent inappropriate hospital stays. Crisis beds can be available so they do not have to live in hospitals while awaiting residential placement. If individuals are dropped off at the hospital, services need to be in place to provide safe, timely, discharge to placements in the community.

1. Determine the Scope of the Problem

The volume of complaints received by the DD Ombuds shows that the unnecessary hospitalization of people with developmental disabilities is a systemic issue, but there is not enough data available to determine the full scope of the problem or to guide long-term strategic investments. DDA does not currently track this information and neither do the hospitals. Changes need to be made to collect sufficient data about people with developmental disabilities who are taken to the hospital. Data needs to be collected to determine why DDA clients are being dropped off at hospitals without a medical need, how long they are hospitalized, and to where they are discharged. Use this data to inform additional systemic solutions.

Specific recommendations:

- Require an incident report when a DDA client is taken to a hospital or other medical institution for any reason.
- Require an incident report when a service provider terminates services to or discharges a DDA client.
- Improve DDA incident report tracking system to capture data on inappropriate hospitalizations, length of stay and discharge locations.
- Develop mechanism to track when a person with a developmental disability is unable to access a bed in a mental health facility when referred by a designated crisis responder for involuntary treatment.

2. Invest in community resources to prevent and address crisis

A. Expand the number and types of specialized providers.

Complaints to the DD Ombuds highlight difficulties individuals and their caregivers encounter in accessing additional supports to prevent further decline in health or behavior. Individuals and their caregivers reported that it is very difficult to obtain any services from specialty providers, such as mental health or behavior assessment; medication management; or technical assistance and consultation, to address a change in behavior. Problems with access to these services arise due to lack of service capacity or due to the provider's inexperience with people

with developmental disabilities. This indicates DDA needs to expand the number and types of specialized providers it contracts with so DDA clients, caregivers, and support staff can access specialists and get support at the first signs of behavior change or decline.

Specific recommendations: DDA contract directly with specialists who can provide the following services throughout the state:

- Psychological assessments, such as Full Scale Intelligent Quotient (FSIQ) and risk assessments;
- Technical assistance and consultation on behavior supports for family caregivers, staff, and medical providers;
- Behavior supports and personal care for people with developmental disabilities living in hospitals;
- Therapeutic mental and behavioral health services; and
- Medication management.

B. Increase direct service professionals' wages.

Residential providers need to be able to hire and retain skilled staff to work with individuals. Issues of turnover and new staff training contribute to a provider's ability to identify changes in their clients and to adapt appropriately to the client's needs.

Specific recommendations: Increase financial investment by the state in residential service providers so they can hire and maintain a highly skilled and stable workforce to support individuals with developmental disabilities.

3. Increase capacity of crisis placements for individuals with developmental disabilities

DDA crisis diversion beds are a community residential placement designed to provide services to individuals in crisis so they do not have to be hospitalized or institutionalized. The individuals the DD Ombuds worked with have struggled to access diversion placements due to lack of bed capacity. As a result, individuals are not able to access diversion beds before they are hospitalized, or are not able to be discharged to a diversion bed from the hospital.

Specific recommendations: Increase diversion bed capacity so individuals with developmental disabilities have an appropriate placement available if they experience a crisis and need residential services.

Contact: Betty Schwieterman, Office of Developmental Disabilities Ombuds

Email: betty@ddomuds.org Phone: 833.727.8900 ext. 209